

Barriers and Facilitators to the Transition from Pediatric to Adult Cancer
Survivorship Care

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Background

There are over 325,000 pediatric cancer survivors in the United States today, thanks to the substantial progress in the treatment of the disease and 80% of children who are diagnosed with cancer today will survive^{1,2}. However, many cancer survivors will develop a variety of chronic conditions as a result of the type of cancer and its treatment. Oeffinger et al have reported that the cumulative incidence for chronic disease 25 years after the completion of treatment in pediatric cancer survivors is 66% and increases to 73% 30 years after treatment, when many of these patients are approximately 40 to 50 years old³. In addition, 20-30% of survivors develop late effects that are considered debilitating or life-threatening¹. Formal cancer survivorship care has been a fairly recent development in oncology, with the goal of monitoring cancer survivors' health and well-being for the rest of their life. This follow-up is critical in identifying any chronic conditions that develop as a result of their cancer diagnosis that may not appear for years after the completion of the treatment, which can lead to earlier detection and potentially better outcomes from earlier treatment². However, less than one-third of young adult survivors of pediatric cancer have reported attending survivorship focused care, and this amount further decreases when the time since diagnosis increases⁴.

There has been extensive debate about the recommended model that will best facilitate long-term care for this population, with the two preeminent systems being care within the treating

pediatric center and transitioning patients to either an adult cancer survivorship program or to an adult primary care provider. In one survey of 179 institutions of the Children's Oncology Group, 87% of members reported providing survivorship care in their organization. Once the survivors they treated reached adulthood, 47% of these groups had models of care that involved transition these individuals to adult providers, while 44% reported following their adult survivors indefinitely⁵. It has been found that young adult cancer survivors benefit from transitioning to adult care, as these providers are often better positioned to evaluate and manage a large number of chronic conditions, given their general population has similar issues (albeit at an older age)³. In addition, these providers have extensive connections to educational, vocational, and other support services that may need to be provided to these adult survivors³.

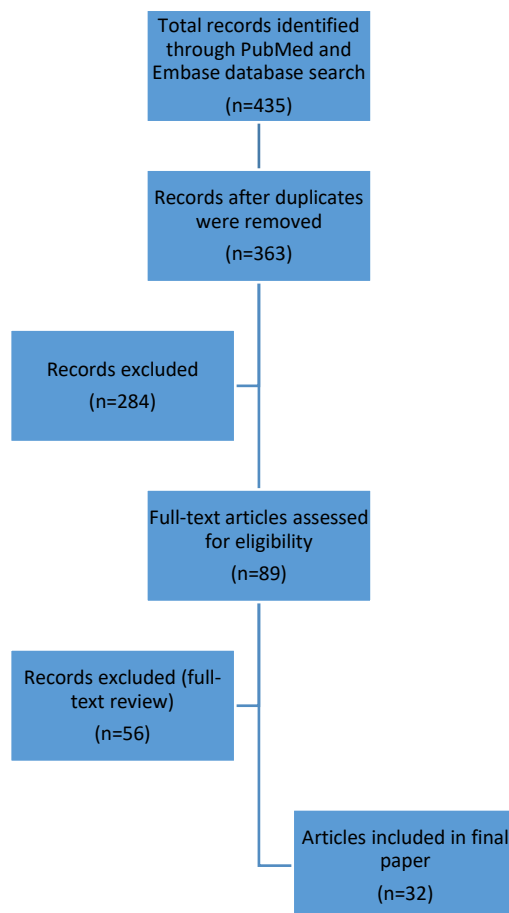
Many avenues of research in cancer survivorship is focused either on issues relating to adult or pediatric survivorship health care, but limited research has been dedicated to looking at the transition of cancer survivors from pediatric cancer patients to adult long-term care. The goal of this research is to summarize the literature in this area, looking at what prevents young adult and adult survivors of pediatric cancer from moving to adult-based care and describe models that may help to improve the transition from pediatric to adult care and retain this vulnerable group in long-term follow-up for chronic conditions.

Methods

Major journal databases such as PubMed and Google Scholar were searched for relevant literature on the topic. The search terms that were used included "transitions of care", "pediatric", "adolescent", "cancer", "survivorship", and "follow-up care" and variations on these terms. Articles that had these terms in their title or abstract were included in the initial extraction of included articles, and duplicates were removed. Exclusion criteria included any articles that

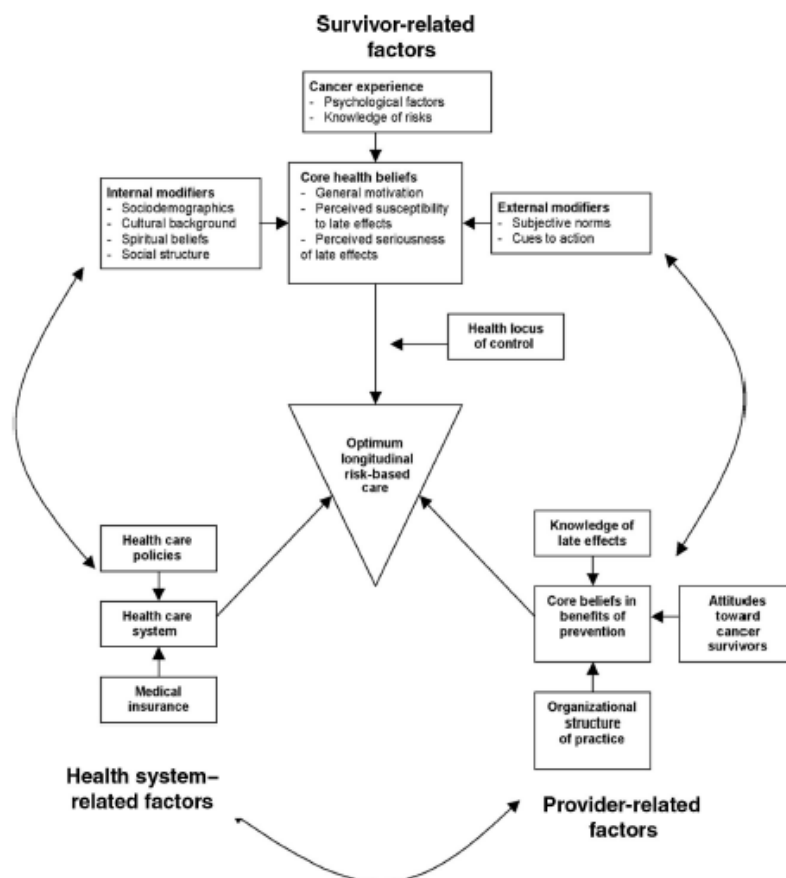
are not about cancer, any articles that are not in English, and any articles that discussed the transition from adolescence to adulthood without discussing transition of medical care services. After initial identification of potential articles, a full review of the title and abstract, followed by a review of the full text was conducted in order to determine the articles included in the analysis. Figure 1 shows the number of articles used in the final analysis, in addition to the number of articles that were excluded at each part of the process.

Figure 1. PRISMA Chart



The barriers that were identified from the literature review were organized into general themes identified by Henderson et al's Optimal Risk-based Care Model shown in Figure 2⁶. This model describes the factors that contribute to the best risk-based care for pediatric cancer

survivors. It shows barriers that impact a successful transition will originate from those who are a part of the process. This model addresses all the major stakeholders with the exception of the family caregivers, but the barriers experienced by caregivers could be considered external modifiers that could impact survivor-related factors. It also shows how each of the different stakeholder factors can impact each other and the various factors within each stakeholder that are key to the barriers of that particular group.



Barriers were organized by the various stakeholders that are a part of the cancer survivorship transition process, which include the patients, their families, pediatric health care providers, adult health care providers, and the healthcare system. Facilitators were more difficult to categorize

into distinct groups, as there are considerably fewer facilitators that were discussed in the literature compared to barriers, so general themes were identified and listed.

Results

Out of 435 articles initially identified in the database search, 32 articles were used in the final analysis. The articles that were studied typically fell into one of three categories: a literature review of articles in the area of transitions from pediatric to adult cancer care, summary papers that describe the trajectory of pediatric cancer patients, and articles that identify barriers and facilitators in transition as a part of a study in implementing a particular transition model in their practice. The data was gathered through the literature or through qualitative interviews of the stakeholders, particularly the patients and their families.

Barriers

Table 1: Identified Barriers to Transition of Adolescent and Young Adult Survivors of Childhood Cancer*

Patients	Family Caregivers	Pediatric Providers	Adult Providers	Health Care System
<ul style="list-style-type: none"> • Lack of financial independence • Poor health insurance coverage • Lack of maturity or health care self-management skills • Lack of knowledge about cancer diagnosis or late effects • Belief that they do not need to receive follow-up care • Have trauma related to the cancer experience • Confusion about where to get adult-centered care • Emotional preference to seeing pediatric provider • Lack of trust in adult provider • Lack of access to specialty providers or survivorship clinics • Belief that cancer is an experience that should be kept in the past • Non-white race and ethnicity 	<ul style="list-style-type: none"> • Reluctance to lose control of their child's health care • Established trust and connection with pediatric providers • Protectiveness of their survivor • Lack of trust in adult providers • Lack of knowledge about cancer and late effects 	<ul style="list-style-type: none"> • Inability to "let go" of their patients • Lack of trust in adult providers • Feel more comfortable continuing to care for patients • Challenges promoting autonomy and independence in patients • Identifying correct amount of information that can be provided without overwhelming the patient • Limited tracking or monitoring of patients' other appointments • Lack of provider communication about what is being done in the survivorship clinics • Concern about long-term survival of patient 	<ul style="list-style-type: none"> • Lack of reimbursement for the care provided • Lack of access to appropriate resources to manage these patients • Lack of knowledge about the late effects of cancer that these patients can experience • Difficulty in decision-making when there is a conflict between COG recommendations and adult provider recommendations 	<ul style="list-style-type: none"> • Lack of patient insurance • Overall high cost of care • Lack of available physicians who can provide long-term care • Few formal transition programs for any condition • Gaps in communication between providers • Lack of referral networks between pediatric and adult providers • Confusion about what roles oncologists, survivorship programs, and primary care providers should hold • Lack of funding for research and transition programs • Issues with health care privacy and guardianship as well as the transfer of information between providers and survivors
* Source of information: Refs. #1-3,5-24				

Patients

Although there were many barriers identified for patients, several of the barriers were selected as ones that were present in multiple articles and were listed as having the most impact

on the transition process. The first is that patients often do not have financial independence at the time of the transition, as many of them are just starting their careers or attending school. This means that they are on their parents insurance or have poor coverage due to unemployment or poor health benefits, making it difficult for them to pay for the care that is needed on a regular basis.^{2,6-13} Another barrier is the lack of maturity or health care self-management skills that can result from being used to pediatric providers (and parents) taking care of their needs.^{1,3,6,8,12,14} A third barrier is the lack of knowledge and need for more information about their past treatment and information about future risks, as well as lack of access to their medical records in order to obtain this information.^{1,3,6,8,11,12,14-18} A final major barrier is they avoid cancer care, even if it is not in the same hospital, either because they feel that they are at a low enough risk that it does not warrant follow-up^{2,3,19} or because they have experienced trauma during their cancer experience and want to avoid triggers that can force them to relive those memories.^{2,6,9,14,20}

Other barriers include an emotional preference of seeing their initial care provider^{2,5,11,21}, and these concerns can stem from a lack of trust in adult primary care providers or oncology groups to provide the same level of care and expertise to a patient population that they may not be as familiar with^{1,6,12,14}. This can lead to concerns of being in limbo from survivors with confusion about who or where they should seek support from in the event that they do need services in their community.^{3,12} Additional barriers are related to the time in a patients' life that they would be transitioning. Many of these individuals are attending college, starting careers, and starting families. This can lead to these individuals lacking access to specialty providers in their locations or survivorship care programs that are able to work with patients further away and their higher level of mobility makes it difficult to establish continuity of care.^{1,3,5,11,12,17,22} An additional psychological factor that can be a barrier is the belief that cancer treatment is an event

that should be kept in the past and not be part of their current identity as it will result in being ‘different’ than their peers and interfere with them wanting to live a “normal” life.^{9,19,20} Finally, race and ethnicity has also been shown to be an important factor to access cancer-related care. Non-white populations of adults have poorer rates of access to cancer screening and cancer care due to cultural, socioeconomic, and environmental factors. Specifically, for childhood cancer survivors, non-whites have been shown to have higher rates of nonattendance in a pediatric survivorship clinic.^{9,10}

Caregivers

The majority of barriers that were experienced or expressed by family caregivers to the pediatric cancer survivor focused on emotions related to the transition process as well as the cancer experience. Caregivers felt the need to continue to have a strong amount of control in their survivor’s cancer care, which they may feel is reduced if a patient is transferred to adult care.^{1,3,6,9,11,12,14} In addition, these caregivers may feel protective of their child and the possibility of them needing to go somewhere else to receive care could result in them resisting the transition.^{1,3,6,9,12,14} Another barrier is the lack of trust that the caregivers can experience when faced with a new provider that they do not have a relationship with or know as well as the pediatric provider.^{1,3,6,9,12,14} The final barrier that caregivers experience is their own lack of knowledge about the cancer diagnosis or late effects of treatment, which could lead to them over or underestimating the risks with long-term follow-up.^{6,11,12,14}

Pediatric Providers

One of the primary barriers across several articles is the inability of the pediatric care team to “let go” of their patients and allow them to transition to adult care.^{1,3,5,8,11,12,14,23,24} This

may contribute to their lack of trust in adult providers or pediatricians to provide care to their patients of the same quality.^{1,3,11,12,14} They may also feel comfortable in caring for pediatric cancer survivors, which can lead to them being more willing to maintain the status quo, especially given their knowledge of late effects.^{1,3,12,14} There have also been concerns about the challenges of promoting independence and autonomy in children with chronic health problems^{8,23} and the correct amount of information that can be provided without overwhelming the patients and not setting expectations regarding transition to a survivorship clinic.² They may also be concerned with about the long-term survival of the patient, especially if their disease was particularly severe.^{12,23} The final barrier are communication challenges within the medical system. Some specific issues that emerged included no or limited tracking or monitoring of patients' other appointments and a lack of provider communication about what is being done in the survivorship clinics.^{2,3,11,16,22,23}

Adult Providers

Within the adult provider community that is receiving the pediatric cancer survivors, the lack of reimbursement for the care provided was considered a major barrier that would need to be addressed.^{3,5,11,12,14} These providers often also lack access to appropriate resources to manage these patients. These can include the considerable time/resource constraints and difficulty in coordinating appointments and dealing with inconveniences that are involved in caring for a patient with complex medical histories and multiple chronic conditions that need to be monitored.^{2,3,11,12,14,16} Another important issue with adult providers, either primary care providers or adult cancer survivorship centers, is that they often feel that they lack the knowledge about the late effects of cancer that these patients can experience^{1,2,5,6,11,12,14,21,24} as well as treating chronic illnesses in younger patients.^{3,21,22} The final barrier is the difficulty in decision making that can

occur when there is a conflict between Children’s Oncology Group recommendations for risk-based care and adult provider recommendations.⁵

Health Care System

The primary barrier that the health care system inflicts is the creation of access issues for patients. These include the lack of insurance faced by patients at the age that they traditionally transition to adult care, the overall high cost of care, and the availability of physicians, as insurance policies often cover limited rosters of physicians which can make it difficult to find a provider that has the expertise required for providing long-term care.^{2,6,11,16} Health care systems also often have very few formal transition programs for any condition, but especially ones that are a part of pediatric cancer programs³ and this causes barriers with gaps in communication between providers as well as a lack of referral networks that pediatric providers can use to link patients to adult providers.^{1,11,15} This can lead to confusion about what roles oncologists, survivorship programs, and primary care providers should hold, which varies from model to model.²

Another systems-related barrier is the lack of funding for research and transition programs, reducing the incentives to create dedicated cancer survivorship and transition programs.³ A final barrier is there are problems with health care privacy and guardianship as well as the transfer of information between providers and survivors.¹¹

Facilitators

Table 2: Identified Facilitators to Transition of Adolescent and Young Adult Survivors of Childhood Cancer*

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|---|
| <ul style="list-style-type: none">• Having an adult provider who is knowledgeable about late effects• Integrating institutional policies describing transitional process and sets guidelines• Acknowledging transition of care as another phase of cancer treatment |
|---|

- Having a pre-determined time that the patients will transition and locations where they can receive care
- Providing flexibility to fit the program to the patient's life after care
- Identifying multiple adult providers willing and educated in the health care needs of young adults
- Establishing early communication between pediatric oncology survivor services and adult practitioners
- Establishing formal partnerships between pediatric and adult programs
- Providing multiple options for a range of specialty services in the community
- Initiating of the transition process only at a time of health stability
- Assessing the readiness of the patient
- Providing financial resources to both patients and adult providers to support continued care
- Providing training to the adult health care providers involved in the transition about pediatric cancer survivorship and the late effects
- Providing training to patients and their caregivers about their disease with associated late effects
- Providing training to patients and their caregivers in skills in health care self-advocacy and management of their conditions
- Providing written or electronic resources that patients can refer to with clear sets of recommendations
- Providing contact information for patients to providers if they have additional questions or concerns
- Having face-to-face meetings with survivors and providers,
- Providing opportunities to discuss the transition with other survivors
- Integrating the nuclear family at survivorship visits
- Patients who were better able to integrate a positive cancer identity and mature from the process and perspective
- Patients who fear cancer recurrence

* Source of information: Refs. #1,2,3,9,11,14,15,18,19,21,25,26

One of the primary facilitators that was mentioned by multiple articles was that both survivors and pediatric providers prefer to have an adult provider who is knowledgeable about late effects.^{3,9,11} In addition, integrating institutional policies describing the transition process and setting guidelines as an acknowledgement that transition of care as another phase of cancer treatment.^{1,3,25} It should be built into the foundation of a cancer survivorship program when and where patients will go when they reach the age of transition, which provides a strong blueprint which can then be manipulated to fit each survivor's needs.^{3,11} As a part of this, identifying several adult services willing and educated in the health care needs of young adults with childhood-onset chronic health needs is imperative to a successful long-term transition of health care.^{3,11} Once these providers are identified, early communication between pediatric oncology survivor services and adult practitioners should begin in adolescence to avoid gaps in medical care and to allow ample time for all parties to become familiar with the medical and psychosocial

concerns of the pediatric cancer survivors.^{1,3,7,11,25} Having this built-in coordination of services between pediatric and adult providers is key.^{3,11} Establishing formal partnerships between pediatric and adult programs can make this process easier³ and providing multiple options for a range of specialty services in the community can ensure that patients receive the correct follow-up care at the correct intervals.^{2,11} This initiation of the transition process should occur only at a time of health stability, not during a health care crisis¹¹ and after assessing the readiness of the patient in order to ensure that they are prepared emotionally and are equipped with the correct information.³ None of these facilitators will have an impact, however, if patients are unable to pay for the services they receive. Therefore, another key facilitator is additional financial resources to both patients and adult providers to support continued care, including more financial support from nonprofits during the posttreatment period.²

Another major facilitator to the transition of pediatric cancer survivors to adult providers is ensuring that everyone has all the information they require before the transfer is complete. This includes providing training to the adult health care providers involved in the transition about pediatric cancer survivorship and the late effects that might occur.³ Patients and their caregivers should also receive education about their disease with associated late effects, as well as ways to build skills in health care self-advocacy and management of their conditions.^{1,3,14,15,26} This education should also come in a written or electronic form that patients can refer to with clear sets of recommendations for them to follow once they leave the pediatric cancer center, as well as contact information for providers if they have additional questions or concerns.^{2,3,11,14,21} In addition, there have been findings that indicate that face-to-face meetings with survivors and providers, as well as the opportunity to discuss the transition with other survivors, were

extremely helpful in ensuring that the patient is comfortable enough with the process and has established relationships with the new provider.²¹

There are some psychological and familial factors that can impact transition. Cancer patients often rely on the nuclear family to be present at survivorship visits as they may not recall their cancer experience and can assist in building their skills in health care management.^{9,15} Involving the caregivers in the transition process can be critical to ensuring that the patients follow the recommendations of the long-term care plan. For patients themselves, those who were better able to integrate a positive cancer identity and mature from the process and perspective are more likely to successfully transition than those who did not.^{18,19} Fear of recurrence was also a potent motivator to committing to adult follow-up care, as they feared that if they did not go to appointments, then the cancer may come back and be detected at a later stage.¹⁸

Discussion

As more pediatric cancer patients survive their diagnosis, these patients will begin to experience side effects caused by their cancer and treatment. It is critical that these individuals continue to receive long-term follow-up that can monitor for the emergence of these late effects and provide treatment as quickly as possible.^{1,2} However, many of these patients continue to be seen by their pediatric provider or drop out of follow-up completely.^{4,5}

This review drew from literature in the field in order to identify the barriers that stakeholders in this transition process are experiencing as well as interventions or experiences that could facilitate a successful transition. Results indicated that a substantial barrier for pediatric providers, patients, and family caregivers was a lack of trust in the adult providers to provide a similar level of care to the pediatric providers. For adult providers, a lack of resources, as well as

a lack of knowledge in such a highly-specialized area as late effects of pediatric cancer patients were obstacles in volunteering to accept new adolescent and young adult patients into their practice. Health systems are working with a lack of resources, as well as problems establishing formal connections between pediatric and adult providers. However, if a pediatric cancer treatment program can build the knowledge of adult providers, as well as patients and their families, this can assist in reducing the problems around the lack of trust in adult providers to provide high quality care to these patients. In addition, the establishment of early communication and formal linkages between the pediatric and adult providers has been shown to smooth the transition to a new doctor and reduce the amount of uncertainty and fear that patients may experience.

Findings from this research may help inform pediatric and adult cancer providers of the issues faced by transitioning population and potential interventions that could be used in order to help resolve the problem. Several models have been developed as frameworks that practices can use when developing transition systems for their patients, although research is still determining which model is the most successful in transitioning patients to their adult physician. Eshelman-Kent et al describe 5 models that can be used to care for adolescent and young adult survivors of pediatric cancer: Cancer Center-Based Model Without Community Referral, Community Referral Model, Hybrid model or Combined Cancer Center and Community Based Model, Postal, Internet, or phone systems, and Adult Oncologist Model.⁵ If a model can be identified as a best fit for a practice, and the lessons learned from facilitators were integrated in order to mitigate as many barriers as possible, this could build a pediatric practice that can successfully transition their pediatric patients to adult long-term care.

However, these facilitators do not become a part of a health care system organically and building in these systems is an expensive endeavor, both in the amount of resources needed and the time that will need to be committed in order to create a high-quality transition program within a pediatric oncology provider's health care system. Therefore, policymakers as well as grant-providing organizations with a focus on pediatric cancer care should make it a priority to provide support for these patients in the form of resources to ensure that survivors of pediatric cancer receive the quality long-term care that they need.

Research in the area of barriers and facilitators needs to continue, focusing on how to best implement interventions that best promote the facilitators will be key and the level of impact that each barrier can have on a patient's willingness or ability to transition to adult-based care. Once these have been identified, it will ease the burden on providers to make a determination on the multiple models that are currently available and reconcile them with the guidelines that are still being developed today. Only then can pediatric cancer survivors ensure that they are receiving high quality care in adult setting, providing them with the opportunity of living a long, health life.

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